DOCUMENT RESUME

ED 355 754 EC 302 013

AUTHOR	Mohesky-Darby, Julie; And Others
TITLE	Setting a New Course: Defining Quality Lifestyles for Students with Dual Sensory Loss.
INSTITUTION	Kansas State Board of Education, Topeka.
SPONS AGENCY	Department of Education, Washington, DC.
PUB DATE	Sep 92
NOTE	23p.; Developed by the Kansas Services for Students with Deaf-Blindness Project. For related documents, see EC 302 011-012.
PUB TYPE	Guides - Non-Classroom Use (055)
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	Attitude Change; Change Strategies; Deaf Blind; Elementary Secondary Education; Evaluation Methods; Family Involvement; Normalization (Handicapped); *Parent School Relationship; Personal Autonomy; Policy Formation; Preschool Education; *Quality of Life; *Severe Disabilities; *Student Development
IDENTIFIERS	*Kansas

ABSTRACT

This guide was developed to assist families and professionals working with people having severe disabilities to improve the overall quality of life these individuals experience. An introduction contrasts new attitudes (such as emphasizing individual strengths and personal control and autonomy) with existing practices which often focus on students' inabilities, continually "prepare" students, and replace the individual's choices with "expert" decisions. A section on defining quality lifestyles for students with dual sensory loss considers basic assumptions about quality of life, defining basic needs, identifying individual preferences, and the quality of life approach. This approach is further discussed in a section which offers guidelines for evaluating current policies and practices and for developing and implementing programs. For use of educators and parents, two tables offer specific suggestions to promote quality of life at the preschool, elementary, and secondary levels. Another section stresses the key role of families in fostering five quality of life outcomes: choice, competence, respect, community presence, and community participation. The final section describes the relationship of programs for students with disabilities to Kansas programs for the improvement of education for all students. (DB)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☐ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

ED355754

Setting a New Course: Defining Quality Lifestyles for Students with Dual Sensory Loss

EC 302013

Published by

Students with Deaf-Blindness Project
Kansas State Board of Education

September, 1992

BEST COPY AVAILABLE

Kansas State Board of Education
Approved 4/92

Strategic Directions for Kansas Education

The Kansas State Board of Education is charged with the general supervision of public education and other educational interests in the state. While clearly acknowledging the role and importance of local control, the State Board of Education has the responsibility to provide direction and leadership for the structuring of all state educational institutions under its jurisdiction.

The beginning place for determining the mission for the Kansas State Board of Education is the assumption that all Kansas citizens must be involved in their own learning and the learning of others. It is the combined effort of family, school, and community that makes possible the development of a high quality of life. It is the parent who is the first "teacher" of children. As we grow older, we learn that the school, the workplace, and the community support our lifelong learning and our training and retraining. The Board recognizes the responsibility it holds for Kansas educational systems and promoting quality education programs. The mission for Kansas education is:

To prepare each person with the living, learning, and working skills and values necessary for caring, productive, and fulfilling participation in our evolving, global society.

We believe that the strategic directions for the structuring of Kansas education must be organized to:

- create learning communities
- develop and extend resources for parenting programs and early childhood education
- expand learner-outcome curriculum and learner-focused instruction
- provide inclusive learning environments
- strengthen involvement of business and industry in education
- provide quality staff and organizational development.

Kansas State Board of Education
Kansas State Education Building
120 S.E. 10th Avenue Topeka, Kansas 66612-1182

Board Members

Mildred G. McMillon, Vice Chairman District 1	Kathleen White District 2	Paul D. Adams District 3	Connie Hubbell District 4	I. B. "Sonny" Rundell District 5
Bill Musick District 6	Wanda Morrison District 7	Evelyn Whitcomb District 8	Tim Emert, Chairman District 9	Gwen Nelson District 10

Lee Droegemueller
Commissioner of Education

An Equal Employment/Educational Opportunity Agency

The Kansas State Board of Education does not discriminate on the basis of sex, race, color, national origin, handicap, or age in admission or access to, or treatment or employment in, its programs or activities. Any questions regarding the Board's compliance with Title VI, Title IX, or Section 504 may be directed to the Title IX Coordinator, who can be reached at (913) 296-2424, 120 S.E. 10th Avenue, Topeka, Kansas 66612-1182, or to the Assistant Secretary for Civil Rights, U. S. Department of Education.

Setting a New Course: Defining Quality Lifestyles for Students with Dual Sensory Loss

Developed by
Kansas Services for Students with Deaf-Blindness Project
Special Education Outcomes
Kansas State Board of Education
120 S.E. 10th Avenue
Topeka, Kansas 66612-1182
(913) 296-2191

Julie Mohesky-Darby, Deaf-Blind Outreach Specialist
Pam Kohlhepp, Family & Early Childhood Specialist
Jane Rhys, Project Director

Services for Deaf-Blind Children and Youth, Project #H025A90001, is funded by the Department of Education in the amount of $404,124.00 for a three year period, October 1, 1989-September 30, 1992, representing 65.5 percent of the total cost of the project. Information contained in this publication does not necessarily reflect the views of the Department of Education.

TABLE OF CONTENTS

Acknowledgements i

Introduction 1

Dichotomy: Vision vs. Practice 2

Setting a New Course: Defining Quality Lifestyles for Students with Dual Sensory Loss 3

Basic Assumptions About Quality of Life 3

Defining Basic Needs 4

Identifying Individual Preferences 4

The Quality of Life Approach 4

A Quality of Life Approach to Special Education 5

Where to Begin 7

Suggested Activities for Educators 9

Family Participation in Quality of Life Planning 13

Suggested Activities for Parents 15

New Directions for Kansas Education: A Quality Life for All Citizens 19

References 21

ACKNOWLEDGEMENTS

The staff of the Kansas Services for Students with Deaf-Blindness Project at the Kansas State Board of Education would like to acknowledge those who assisted in the development of this resource. We would like to express our appreciation to Michael McCarthy, formerly with the Helen Keller National Center-Technical Assistance Center (HKNC-TAC) for his valuable input on Personal Futures Planning. Special thanks to Dr. Pat Barber, University of Kansas, who compiled and developed information contained within this document.

A work group consisting of parents, adult service providers, teachers, university staff and project staff provided input into the development of this resource. The work group members listed below are gratefully acknowledged for their contributions of time and effort in providing input into the development of this publication.

Mary Ann Adams, Coordinator, Shawnee County Cooperative

Sandra Andrews, Deaf-Blind Specialist, HKNC-Kansas Project

Susan Arnold, Parent

Pat Barber, Consultant, Beach Center on Families and Disability,
University of Kansas

Marnie Brown, State Transition Counselor

Michelle Gaskell, Teacher, Brown Co. Educational Cooperative

Sondra McDonald, Parent

Julie Mohesky-Darby, Deaf-Blind Outreach Specialist,
Kansas Services for Students with Deaf-Blindness Project

Mary Morningstar, Director, Full Citizenship

Kerry Ottlinger, Coordinator, Facilitating Least Restrictive Environment for
Students with Deaf-Blindness Project

Bob Taylor, Lead Teacher, Kansas State School for the Visually Handicapped

Barbara Thompson, Associate Professor, University of Kansas

Susan Williamson, Education Program Specialist, KSBE

INTRODUCTION

"Full retirement at age 18 is not an aspiration many people have or can afford, but for many graduates of special education programs, it is the future. It is our obligation to set a different course" (Judy Hegenauer, California Advisory Commission on Special Education, cited in Wingert, 1991).

Society has begun to set a new course for people with severe disabilities. Today more than ever before, family members, professionals, friends and neighbors are working collaboratively to support a better quality life for individuals within the community-those whom, in the recent past, were often denied the opportunity to participate in the normal "round of life."

This changing vision of people with severe disabilities and deaf-blindness has motivated a new set of assumptions about their rights, needs, and preferences. The new vision emphasizes individual strengths, rather than deficits, and supports the belief that all people have or can acquire the competencies they need to direct and control many aspects of their lives. Even further, it means that all persons with severe disabilities should expect to:

- live and participate in the community
- enjoy meaningful relationships with their family and with people in the neighborhood, at work, and in a variety of community settings
- participate in activities that are personally rewarding
- participate in activities that are valued by others
- make personal choices that affect their daily lives and their future

Did You Know?

- Few students with disabilities move from school to independent living in their communities.
- Secondary special education programs may have minimal influence on the adjustment of students to community life.
- Few graduates of special education programs or services find adequate employment.

Edgar, E. (1987). Secondary programs in special education: Are many of them justifiable? Exceptional Children, 53, 555-561.

Increasingly, these expectations are being met for many individuals, but efforts should be aimed at transforming these visions and expectations into reality for every person with a disability. To do so may call for a re-evaluation of our present system of services and support, including a thoughtful examination of how educational services can be fashioned to ensure that these expectations are being met.

A variety of educational programs that support a quality life for persons with severe disabilities and deaf-blindness are being implemented in many schools across the country. Efforts toward full inclusion in the educational setting, the development of functional curricula and community-based instruction, and the current emphasis on transition planning are some of the important ways in which educators are supporting the goal of community participation. Yet, these programs represent only a portion of the educational programs and practices implemented on a daily basis for students with severe disabilities. They do not define a total curriculum aimed at enhancing and supporting a good life for these individuals.

Our challenge is to look beyond the implementation of specific programs to general educational practices that have an impact on each student's quality of life.

One way to examine the current service system is to evaluate its "fit" with our new expectations for people with severe disabilities. As we increase our efforts to develop services that reflect our new vision, we may also be adhering to some practices that do not. Consider the following differences

between the new vision for people with severe disabilities and some current educational practices.

Dichotomy: Vision vs. Practice

NEW VISION: Emphasize individual strengths and abilities.

CURRENT PRACTICES: The educational system emphasizes students' deficits. Educational goals, objectives, and intervention strategies tend to focus on students' inabilities, rather than their abilities.

Educational services are based on a time- and context-limited view of the student: student goals and related programs are developed within the framework of the school year; intervention strategies focus on the students' behaviors in the classroom or school setting; and, professionals attend to specific behaviors or developmental patterns, rather than the total child.

NEW VISION: Ensure active participation in community life.

2

CURRENT PRACTICES: The traditional educational approach assumes that students with severe disabilities including deaf-blindness are never "ready" to participate in the community. We are always in the process of preparing students for life—teaching new skills and competencies—while de-emphasizing participation in current life activities.

Community participation is often viewed as a futures planning or transition issue. This means that preparation for community living may be delayed until the student's adolescent years and not incorporated into the daily activities and experiences important to the student's ongoing development.

Expectations for community participation are guided by service availability, rather than by the individual needs of each student. Planning based on service system options can limit our vision of what is possible for the student and lower our expectations for community participation. Such limitations ignore the person's abilities, needs and preferences, as well as the resources available within the community to support all three.

NEW VISION: Enhance and support personal control and the ability to make choices about immediate and future needs.

CURRENT PRACTICES: Professionals who are responsible for assessing student needs, setting goals, and ensuring outcomes, define students' present skills and determine what they will become in the future. That is, the traditional approach supports a professionally-dominated view of the child's present and future quality of life. It places the expert in a position of authority regarding choices and decisions that affect the students' lives, rather than promoting personal control.

Acting on our concern for enhancing the quality of life of persons with severe disabilities/deaf-blindness means that we must (a) continue to refine our best practices, (b) create new programs and strategies, and (c) revise or eliminate current practices based on outmoded assumptions about what is possible for students with severe disabilities. We need to step away from our daily activities and interactions with students in order to think about each student as a total person, their day-to-day lives, and the ways in which we contribute to the quality of each student's lifestyle. Some initial questions to ask:

1. What is important to your overall quality of life?
2. What do you believe are the important characteristics of a good quality of life for all people?
3. What are your expectations for persons with severe disabilities/deaf-blindness?
4. How can families and professionals support a better quality of life on a daily basis?
5. What can families and professionals do to ensure a good quality of life for these students in the future?

Are we on the right course?

Setting a New Course: Defining Quality Lifestyles for Students with Dual Sensory Loss

Parents want the same experiences for their children with severe disabilities/deaf-blindness that most people desire for themselves. The broad characteristics of quality of life, noted above, describe some of our most basic human needs. These are just some of the characteristics that define what is most important to our lives and what we should expect for ourselves and people with severe disabilities. Our efforts to enhance the lives of others should be guided by a broad set of goals aimed at improving quality of life.

There are a variety of ways in which people can define a good quality of life. Some might emphasize the importance of monetary wealth; others are concerned about a clean environment for their children. What is needed is a common definition that will guide the development of services and supports for persons with severe disabilities including deaf-blindness. The following framework describes some of the important components of quality of life that should be considered as educational programs are planned and implemented.

Basic Assumptions About Quality of Life

The framework begins with a list of the basic characteristics which describe the term "quality of life."

• A quality lifestyle exists in the present as well as in the future.

A good life is not something we should merely hope for, but something we should enjoy on a moment-to-moment basis. As family members and professionals, our efforts to improve the lifestyles of children and adults with disabilities should emphasize the present—their daily lives—while planning for a better future.

• Quality is defined by the individual as they live and perceive life.

There are many ways in which family members and professionals can enhance the lives of persons with severe disabilities. Yet, the individual is the only one who can determine if their life is good or satisfactory.

• The quality of a person's life is the summation of the individual's experiences across a variety of settings.

It includes all aspects of a person's life in the present as well as their aspirations and expectations for the future. A quality of life perspective requires parents and educators to extend their focus beyond the school or home setting to the community at large. It asks us to think about the child or adult as they function in all settings and the various people with whom they interact.

• A quality lifestyle consists of a person's needs and wants.

There are many ways to describe the difference between a person's needs and what they want or desire. The difference between the two is best described as those things that we believe to be important to a quality life for all people (needs), and those things that each individual would identify as important to their own quality of life (wants).

Did You Know?

When asked what would constitute a quality life for their children with dual sensory impairments, parents listed the following major characteristics:

- A safe, comfortable, and stable home
- A social network of "people who care"
- Productive use of their time
- Engagement in work (e.g. paid employment, volunteer work, continued training, or leisure activities) that is personally meaningful, that enhances their self-image, and is valued by society
- Access to varied environments and activities that promote a full and interesting life
- Good health
- To be treated with dignity and worth

Giangreco, M. F., Cloninger, C. J., Mueller, P. H., Yuan, S., & Ashworth, S. (1991). Perspectives of parents whose children have dual sensory impairments. The Journal of the Association for Persons with Severe Handicaps, 14(1), 14-24.

Defining Basic Needs

One method for identifying basic needs is described by O'Brien (1987) as outcomes for a good quality of life. These outcomes are basic expectations for the lives of persons with severe disabilities:

> Community presence: a sharing of the ordinary places that define community life.
>
> Choice: the experience of autonomy both in small, everyday matters and in large, life-defining matters.
>
> Competence: the opportunity to perform functional and meaningful activities with whatever level or type of assistance that is required.
>
> Respect: having a valued place among a network of people and valued roles in community life.
>
> Community participation: the experience of being part of a growing network of personal relationships that includes close friends. (pp. 177-178)

Although listed separately, these outcomes are interrelated. For example, people can gain respect by performing meaningful activities in the community context. On the other hand, a person's choice of employment might limit the ability to expand personal networks. In total, these outcomes, or basic needs, provide us with a broad set of goals which can guide our day-to-day interactions with persons with severe disabilities.

Identifying Individual Preferences

The distinction between needs and preferences is particularly important when making decisions that will affect the lives of others. Within the broad categories that define basic quality of life expectations for people with severe disabilities/deaf-blindness are a variety of alternatives and opportunities, not all of which will enhance the individual's lifestyle. Although it is possible to create opportunities to enhance quality of life, it is not possible to create a "good" life for another person without considering their personal interests and desires. Even further, it is not possible to determine if efforts to improve quality of life are successful without the individual's evaluation of his or her satisfaction or disappointment with various aspect of life.

What are the implications? First, people with severe disabilities/deaf-blindness should be encouraged to express their preferences and feelings, and such expressions should be respected. Second, it is important for them to assess the outcomes of the choices and decisions that they or others make that affects their lives. Because quality of life changes as the conditions of life change, such assessment should be ongoing. Finally, families and professionals must recognize that the lifestyle goals and expectations they may have for persons with severe disabilities/deaf-blindness may not be those that the individuals have for themselves. It is important to anticipate and accept these differences, and most of all, to guard against impositions of values and preferences that might enhance our own lives, but not theirs.

The Quality of Life Approach

These two basic components of quality of life—needs and wants—enable us to focus on the broad characteristics that define our overall expectations for people with severe disabilities/deaf-blindness. At the same time, they acknowledge that people have very different expectations for their own lives. Together, they define a quality of life approach to service provision that requires us to:

1. Take a holistic view of the child or adult.
2. Focus on today as well as tomorrow.
3. Develop services and provide opportunities that will address students' need, preferences, and expectations for a better lifestyle.

A Quality of Life Approach to Special Education

Ensuring a quality lifestyle for people with severe disabilities/deaf-blindness is an ongoing process that should begin at an early age and continue across the life-span of the individual. Competence, choice, respect, and community participation and presence are nurtured throughout the developmental process for all children. The home, school, and community settings provide numerous opportunities that support this ongoing development. All people within the child's community provide the experiences—planned or naturally occurring—that are essential to this developmental process.

These same opportunities are equally important to the development—quality of life—of children and adults with severe disabilities. They, too, will benefit from the planned and naturally occurring experiences that define community participation. The role of educators and families is to provide whatever supports are necessary for the student to participate in and learn from these experiences. In this way, competence, choice, respect, and community participation and presence are built into the developmental process. They become a way of life rather than a future expectation. Ultimately, services and supports are most helpful to children and adults with severe disabilities when they promote a better quality of life.

A quality of life approach does not provide a set of activities or ready-made programs for educators. It does, however, ask us to be creative in our thinking about the student as well as the resources that are available in the home, school, and community. It is an approach that coordinates and builds on many of our current "best practices," all of which can enhance quality of life: individualized education programs; full inclusion; futures planning; transitional services; community-based instruction; circle of friends; and, transdisciplinary planning, as well as assuring that basic needs such as accessible communication systems, sensory adaptations and orientation and mobility services are being met. Yet, it requires that quality of life concerns be the guiding principle for all our interventions with students. The key to this approach is the identification of resources and the development of practices that can be used to provide and plan for a quality lifestyle regardless of the student's age, developmental level, or strengths and disabilities; regardless of the availability of ready-made programs and services within the school and community.

Did You Know?

People engage in meaningful work across a variety of settings—at home, at school, and in leisure and recreational activities—not just on the job.

Children develop attitudes, expectations, interests, habits, and behaviors related to work at a very early age. Beginning in the early years, children need to learn about different career opportunities, observe role models, develop attitudes about work habits and behaviors, and fantasize about what they can be in the future.

Brolin, D. E. (1989). Life centered career education: A competency based approach (3rd ed.). Reston, VA: The Council for Exceptional Children.

Although it is not a specific intervention or planning program, this approach does provide a standard for evaluation of current policies and practices. Here are some examples:

5

- Are school activities designed to support or maintain a network of friends and other caring people who are important to the student's quality of life?
- Do we help students learn hobbies or find ways to enjoy their leisure time?
- Do transitional plans provide the types of opportunities students will need to participate in a variety of activities within the community? Have these plans considered all aspects of a quality life?
- Are students able to make decisions and solve problems—skills important for competence and choice—throughout the school day?

- Do school or district policies and practices support community participation or full inclusion for students of all ages?

- Do students with deaf-blindness have communication systems that are readily accessible to him/her and are usable by non-disabled peers?

- Are sensory adaptations made as needed to allow for maximum inclusion in the general education classroom?

In addition, the quality of life approach can be used for the development and implementation of programs. Some suggestions are listed below:

- Think creatively about the student.

  Here, the focus is on the "total person." In most cases, professionals are not able to observe the student across a variety of settings which limits their perspective of the student's overall quality of life. Family members are the most important source of information. In turn, they can suggest or talk with others who can provide similar or differing perspectives.

- Build on the strengths and abilities of the student.

  While continued skill development is important, students should not be expected to "wait" until we believe they are ready to participate in normal life activities. The strengths approach allows for immediate and ongoing participation in community life. Students need a variety of opportunities to use their abilities and to enjoy successful experiences.

- Develop programs and methods that "fit" the needs and preferences of the student.

  Begin with an assessment of what the student requires for a better quality of life. Work with family members, professionals, and community individuals to identify potential resources to meet these needs and preferences. Once again, existing services may not be sufficient to meet these needs. The more people you can involve in this process, the greater the number of ideas, suggestions, and resources.

- Enhance choice, competence, respect, and community presence and participation in everyday activities.

  There are a variety of ways in which educators can provide opportunities for students to make and act on their choices, develop relationships with school peers, or engage in recreational activities which they enjoy. In addition, students should be encouraged to describe their visions for the future—where they will work or live and how they will spend their leisure time. Less obvious, but equally important to their quality of life, are the types of opportunities that will increase their feelings of self-worth and self-efficacy. In many cases, educators can incorporate new strategies into existing programs and activities.

- Begin the process of future planning regardless of the student's age.

  Future planning should begin now and continue throughout the student's development. This does not mean that decisions must be made about the student's employment or living environment. It does mean that decisions that affect a student's quality of life when they are young will ultimately affect their lives as adults. For example, students who develop a network of caring individuals in the school and community throughout their developmental years will expect and enjoy these relationships as adults. Those who are provided with ongoing opportunities to live, work, and recreate in the community as children will have a natural place in the community as adults.

- Emphasize a team approach to service provision and planning.

  Every person who knows and cares about the student has important information to con-

tribute to the educational planning process. Family members, who know their children best, should work with other team members to identify student strengths and preferences, community resources, and opportunities that will enhance their child's quality of life. Friends, neighbors, and community service providers are equally important to the process.

Open discussions related to quality of life are an important function of the educational team. Team members need to share their individual perceptions of the student's present quality of life and their expectations for the future. In particular, family members should be given opportunities to describe their hopes and concerns about their child's future as well as information about resources, service options, and community opportunities that will support a better life for their child. The purpose of the team is to create a shared vision of their expectations for the student and develop strategies that will lead to the desired result.

- Develop educational goals and objectives that enhance a quality lifestyle.

Quality of life concerns can provide a framework for the development of annual educational goals and objectives. Written goals that build on strengths and preferences, consider the student's day-day-lifestyle, and promote choice, competence, respect, community presence and community participation, are those that will contribute to a better life. A first step might be to review and consider the student's current goals and objectives.

- Develop strategies that will ensure continuity throughout the student's school career.

A student's school career is often marked by constant changes and interruptions that can adversely affect their progress. This is particularly true of staff changes and student transitions from one class or school to the next. At these times, careful planning is needed to ensure that program and quality of life goals are maintained. Because family members are the constant in the child's life, their active participation in transition planning is essential.

Where to Begin

The following chart (Table I) provides suggestions for planning and promoting quality of life for students with severe disabilities throughout their school career. Listed are activities for educators that can be implemented at the preschool, elementary, and secondary levels.

TABLE I
Suggested Activities for Educators

Working with Preschool Students

Provide opportunities for the student to make choices during work and play activities. This could include the selection of free play activities, choosing partners for a game, or picking a favorite song for singing or listening.

Encourage students to learn, work, and play together.

Encourage students to use their free time productively.

Take note of the types of activities, foods, toys that the child most enjoys.

Provide opportunities for the child to repeat successful activities.

Plan outings for the students in the community such as a day in the park or a trip to the zoo. Find activities that will allow the children to meet and interact with people in the community such as organized Easter egg hunts.

Plan activities that will introduce children to a variety of vocational roles through songs, stories, community visits, or games.

If children are not enrolled in neighborhood day care programs, initiate an effort to make this happen. Begin by forming a group of interested individuals who can assist in the development of a plan for student inclusion into local day care programs.

Use a transdisciplinary team approach to develop a holistic program that integrates communication, physical therapy, and other activities.

Assure that each child has a communication system.

Working with Families of Preschool Students

Ask parents to describe the student's normal activities at home: things they enjoy doing, favorite people, and how they spend their time.

Encourage parents to plan parties or outings that will include other children and families.

Encourage parents to find age-appropriate community activities for the child: the local pool, church or synagogue activities, or community picnics. Acknowledge any concerns that parents may have about participation in community activities and help them plan strategies for inclusion.

Discuss the importance of allowing the child to make choices on a regular basis. Ask parents to suggest ways in which they encourage choice at home, and have them select 1-2 strategies that they can implement on a regular basis.

Begin talking with family members about elementary programs for the child. Describe your expectations for full inclusion: what it means, why it is important, how it might work at the elementary level. Encourage families to visit neighborhood schools in order to discuss their expectations regarding inclusion and other facets of their child's program with school staff members.

Suggest that families attend kindergarten round-up at their local school.

Begin talking with family members about the importance of planning the child's transition to the elementary program several months prior to the actual planning process. Allow them to express their concerns about the new school or staff. Explain the importance of family participation in the transition process, ask them to describe their preferred roles in the process, and inquire about how your program can ease the transition for the child and family.

Encourage parents to meet families of other children who have disabilities of all ages. Suggest that they talk with families of children who are enrolled in the elementary program their child will attend.

Invite family members to bring friends, professionals, or community people to school meetings. These

people can provide family members with needed support during IEP and other planning meetings, and they can be a resource for new ideas on community participation.

Support parental decision-making in all aspects of the child's education and be willing to support these decisions. Recognize that parents may have values, expectations, and preferences which differ from your own. These differing perspectives should be acknowledged and discussed as decisions are made about the child's education.

Encourage family members to advocate for their child both at school and in the community. Provide families with whatever resources they may need, e.g. information, referrals, support, to represent their child's best interests.

Share your future expectations for the child on a regular basis. Limit your discussion to a few months from now, next year, or when the child enrolls in elementary school. Allow parents to share similar expectations and any related concerns.

10

Help parents learn about their rights. Provide information about IDEA, ADA, and other legislation that affects their child.

Be careful not to impose your views and expectations. Parents need time to learn about their child, their rights, the service system, and different types of programs, among others. You can be most helpful to families when you provide them with information, answer their questions, support their decisions, and encourage their ongoing participation. Your primary role is to help parents become informed consumers and advocates for their child.

<u>Working with Elementary Students</u>

Develop expectations for full inclusion. Introduce the concept of a student planning team if one has not been formed. This team should include family members, general and special education personnel, related service providers, and other individuals from the community who can assist the core team. The purpose of the team is to work collaboratively toward the development of a plan which will provide a quality educational program in an inclusive setting.

Provide opportunities for students to make choices, learn problem-solving skills, develop independence, and follow directions.

Talk with vocational counselors about the development of goals that focus on vocational skills and in-school jobs. Of equal importance is the development of self-confidence along with the student's ability to take pride in his or her work.

Continue with age-appropriate activities—field trips, parent presentations, or films—that provide information about different employment opportunities.

Continue to develop goals that focus on the child's overall quality of life including those that address leisure time activities, the development of social networks, independence, and others.

Continue to build on the child's strengths and preferences. Provide opportunities that will promote self-worth and self-efficacy.

Take time to think about the child's present quality of life and ways in which you can promote a better lifestyle.

Identify student preferences related to work and leisure time.

Help students learn about different types of work roles.

<u>Working with Families of Elementary Students</u>

Discuss the MAPS process and Circle of Friends program with families.

Support parents in their efforts to advocate for services and programs that facilitate full inclusion, prepare the student for community participation, and enhance the child's present and future quality of life.

Encourage parent-to-parent activities. Link parents with other families of children with disabilities, including families of older children.

Discuss ways in which parents can provide opportunities for their child to develop skills that are important for employment: learning responsibility, learning to work cooperatively with others, increasing their time on task, and others.

Discuss ways in which parents can promote choice and decision-making on a daily basis.

Work with families to identify community activities that are appropriate for the child.

Talk with families about how the child can use their time productively at home, such as helping with household tasks or developing hobbies.

Discuss your future expectations for the child. Describe school activities that are preparing their child for community participation. Encourage parents to talk about their expectations and concerns.

Working with Secondary Students

Develop educational goals that focus on the student's preparation for community living. Continue to include goals that will enhance the student's current as well as future quality of life.

Work with the vocational counselor to identify programs and activities that can be implemented in the classroom. Discuss the types of skills the student will need for employment or other productive work. Be sure to provide information to the vocational team about the student's strengths and preferences.

Develop programs and individual goals for community-based instruction.

Continue to support full inclusion.

Talk with the transition planning counselor when the student is first enrolled in the secondary program. Ask for suggestions about how you can prepare the student for transition. Ask for ways in which you can involve the family in preparing for transition.

Working with Families of Secondary Students

Discuss the transition planning process with the family during the student's first year in the secondary program. Provide them with written information about the program.

Describe the futures planning process and encourage families to work through some or all of the program. Provide written information for their review.

Ask family members to discuss their quality of life goals and concerns related to their child's future. Ask them to identify what is most important for their child's future quality of life. Begin to talk about ways in which the school, family, and community individuals can work together to meet the family's expectations for their child.

Talk with families about specific ideas regarding future work opportunities, community-living options, and other issues related to community participation. Be creative in helping families identify options. Discuss the types of community experiences the student would enjoy or dislike. Consider the student's strengths and special skills. Consider student's health issues, behaviors or other issues that would affect their community participation and think of types of supports he or she will need to benefit from work or leisure activities.

Be sure to keep future planning on the agenda for family meetings. Be sensitive to the fact that some families may not be prepared to discuss these issues. Describe why it is important to begin addressing these issues, and explain the steps you and other staff members are taking to prepare the student for community living. Suggest some possible ways in which family members can help with the process. Let them determine their own point of readiness to discuss these issues. At a minimum, keep them informed until they are ready to participate in the planning process.

Family Participation in Quality of Life Planning

Family members of adults with severe disabilities often talk about the limited opportunities that exist for their son and daughter after graduation. Many parents assumed that the same array of services and supports provided during the school years would be available for the adult in the community. Parents note that there are few service options or that existing services do not meet the adult's nor the family's needs.

Although professionals and parents are working together to build a better system of services for adults with severe disabilities/deaf-blindness, many children and families cannot wait. Even where a variety of services exist, parents often recognize that services alone cannot provide everything that the adult needs or wants. Reliance on the service system alone limits the individual's opportunities to participate in the normal day-to-day activities that most people enjoy in their communities. If we ask what the service system has to offer, we might be missing out on many other life-enhancing experiences.

Did You Know?

Sometimes I look at Cassandra and wonder if she's truly happy with her life—if we're doing everything we can for her. I can't even count the number of professionals who have worked with her since she was born. I know she's getting better, but is this what she needs to make her life happy? Will any of this make any difference when she grows up? Tom and I have talked about her life when she gets older—and ours. Sometimes I'm really hopeful; mostly I'm pretty scared. We don't talk about it too much anymore. We just need to wait and see what happens.

(A mother of a child with severe disabilities)

The notion of planning for a child's future can appear to be an overwhelming task, particularly when the daily tasks of living leave parents and professionals with little energy in reserve to devote to "futures planning." The outcome is that planning may not occur until the child is ready for the transition to community life. Parents have noted some additional reasons for delaying their discussions of the child's future. First, some parents find it difficult, or even if impossible, to deal with the unknown. Too often, families are given little information about what they can or should expect. Second, families are often presented with limited options. The reality that families often hear about is based on what is available, rather than possible. Finally, community supports have not kept pace with our new expectations for people with severe disabilities including dual sensory loss. Although we have set a new course, we have not yet developed all of the supports that are needed to ensure a quality lifestyle for people with disabilities.

All families desire a good quality of life for their children, both now and in the future. Unfortunately, families have had little opportunity to voice or act on these visions. In the past, these broad quality of life concerns did not seem to "fit" the typical goals, objectives, and activities that affected the child's day-to-day existence. The family's holistic view of the child has often been reduced to issues of speech, motor, or social development. Although these developmental issues are very important for families, so are those related to quality of life.

Families can play a key role in bridging the gap between traditional educational issues and quality of life concerns. They are the ultimate decision-makers regarding services and supports for their children, and they can work with professionals to ensure that their child or adult with severe disabilities is provided with opportunities that will contribute to a better life. Family members can begin by thinking about their child's current lifestyle and those things they would desire for their child in the future. It might be helpful to think about the five quality of life outcomes: choice, competence, respect, community presence, and community participation. As family members work through this process, they should remember that desired quality of life outcomes may be different for each family or even for members within a family. In addition, family concerns about quality of life may change over time. Additional suggestions can be found in Table II.

The quality of life approach does not require a special process or carefully planned meetings. Family members can begin discussing these issues with educators and other professionals at informal, IEP or transition planning meetings. They can request information about full inclusion, community-based instruction, or other programs aimed at normalization and community participation. Of course, family members need to discuss these issues with each other, and they might find it particularly helpful to consider quality of life concerns when important decisions need to be made about the child or adult.

Above all, families need to envision what they desire and expect for their children throughout life, share this vision with others who are concerned about the child, and find the support they need to turn these expectations into reality.

TABLE II
Suggested Activities for Parents

Preschool Students

Observe those things that your child does well—his or her strengths. Find opportunities for your child to use these skills in a variety of activities and settings.

Think about those things that your child most enjoys as well as those they dislike. Encourage them to participate in activities that they most enjoy during their free time. Continue to introduce new activities and observe their likes and dislikes. The goal is to help your child find ways to use their free time productively and to provide special times during the day which they can look forward to.

Provide opportunities for your child to make choices on a regular basis. Begin with one or two activities—mealtime or at play—when choices can be provided. Continue to expand into other activities. Once you get in the habit of providing opportunities for choice, it will begun a part of your interactions with your child.

Find or create opportunities for your child to meet new children and adults.

Find or create opportunities for your child to play with children who do not have disabilities as well as those who do. Show these children how to communicate with your child, and encourage them to engage in activities that your child enjoys or does well.

Find or create opportunities for your child to participate in community activities such as picnics, visiting the local zoo, or organized activities for preschoolers.

Plan for success. Children need to develop good feelings about themselves and their accomplishments. Repeat and build on activities and experiences that will enhance their self-concept and feelings of accomplishment.

Get to know your child's educational team. Inform them about your child's needs and preferences. Remember that you know your child best. Participate in decisions about your child's education throughout the school year as well as during IEP meetings.

Begin thinking about your child's transition to the elementary school. Ask about classroom options; things you should consider when making decisions about programs or schools. Take time to discuss your concerns with the child's current educational team. Talk with other families of elementary children and visit the local programs. Think about aspects of your child's program that you would like to continue in the new classroom.

Learn about your child's educational rights, national, state, and local programs that can provide support, resources and information. Information can be obtained from your local school district, the Kansas State Board of Education, parent organizations, or through national dissemination networks.

Elementary Students

Begin by attending kindergarten round-up with your child. This will allow you and your child to meet new children, families, and school staff.

15

Spend time talking with members of your child's new educational team. Discuss the types of programs and activities that you would like them to continue from the preschool program. Help them to get to know your child.

Discuss your perspectives on full inclusion with the new team. Describe the types of activities you would like your child to participate in at school.

Continue to provide opportunities for your child to make choices at home. Children should also be learning how to solve problems and take on responsibilities in the home.

Explore new opportunities for your child's participation in the community: recreational activities and ways to meet new people.

Expand your own network of families of children with disabilities including those who have older children. Families who have older children with disabilities can provide concrete information about

the issues of futures planning, including helpful resources and "how-to" information.

Begin to think about your child's present quality of life and those things that will be important to your child's life next year and five or ten years from now. In what ways would you like to improve your child's life at this time? Talk with other family members, friends, and the educational team about how you might accomplish these quality of life goals.

Develop annual goals that address your child's current quality of life needs and preferences as well as those that will begin to prepare your child for the future. If possible, share these goals with the educational team before the IEP meeting.

Talk with or observe your child in order to learn about his or her interests and preferences related to work, friendships, and community activities.

Stay informed about changes in legislation and other policies that affect your child's current and future services.

16

Provide opportunities for your child to meet adults with disabilities. They can be very special role models and companions for your child and an important resource for your family.

Discuss your child's transition to the secondary program at least one year before your child is enrolled. Consider the issues related to transition that are described in the preschool section, above.

<u>Secondary Students</u>

Begin to prepare for your child's transition to community living. Talk with the educational team about the transition planning process. Ask about the purpose of the process, what it entails, and expected outcomes. It is never too early to discuss transition planning at the secondary level.

Learn about community-based instruction. Work with your child's educational team to identify community sites and activities in order to ensure that community participation is a regular part of your child's program.

Continue the MAPS process and Circle of Friends program in your child's new school or work with other families and the educational team to develop these programs.

Continue to advocate for full inclusion. Work with the educational team to expand the number and types of opportunities your child will have for community participation.

Talk with vocational counselors about their expectations related to your child's future work. Discuss the types of skills your child will need to engage in productive work activities. Learn about activities or opportunities that you can provide at home or in the community that will enhance the development of work-related skills.

Take the time to talk with all family members about expectations for your child's future. Begin by identifying those things that will be most important to your child's quality of life in the future. Next, think about your child's personal desires and preferences. These wants and needs can be used to guide further discussions about specific issues such as employment, place of residence, leisure time activities, community participation, and other issues related to the child's future.

Ask for information about the futures planning process. There are a variety of books and other resources describing this process. Even if you decide not to use it in its entirety, family members can use portions of the process to think about the child's future employment, his or her strengths and preferences, the types of supports your child will need in the community, and many other important aspects related to your child's quality of life.

Begin to think about community resources that will support your child after graduation. Don't limit your list to formal services. Include all resources including people, recreational activities, businesses and services that might have employment opportunities, volunteer possibilities, and transportation for your adult son or daughter within the community.

Talk with the school staff about your child's participation in graduation activities.

Talk with parents of adolescents about ways in which they are preparing for their child's graduation as well as parents of young adults who are presently in the community. Here, it is important to talk with a variety of families in order to gain different perspectives. Don't limit your discussions to families who live in your community. Because services and supports differ from one community to the next, it is helpful to learn about services that do not exist in your community which could be developed locally.

New Directions for Kansas Education: A Quality Life for All Citizens

Kansas is taking important steps toward improving educational quality and equity. At the heart of school improvement initiatives in our state is the underlying belief that all children can learn and all schools can improve. The result will be improved educational "outcomes" and the promotion of a better quality of life for students with disabilities including dual sensory loss.

All Children Can Learn

The educational vision for Kansas emphasizes skills that support full societal participation along with the traditional basic skills provided by our schools. The overall goal is to provide every citizen with the living, learning, and working skills needed to participate in our competitive, global society.

Students will be prepared for lifelong learning and continued career development; business, communities, and schools will promote productive employment for all citizens including persons with disabilities and others who may require a supportive work environment.

Did You Know?

Kansas 2000 reflects a nationwide commitment to the improvement of education for all students:

"The goal of KANSAS 2000 is to make sure that each Kansas citizen will have the skills and values necessary to contribute to our community and to our nation by the year 2000...We believe that it is the combined effort of family, school, and community that makes possible excellence in education and the high quality of life in our state" Joan Finney, Governor.

All Schools Can Improve

One strategy for educational change is the Kansas Quality Performance Accreditation System which addresses school improvement and accountability for teaching and learning at the local school level. By 1995, all Kansas districts will participate in the process of planning improvements that will better prepare all students for societal participation.

Better Outcomes for Students with Disabilities

Families, students, and educators can look for several initiatives that will affect the quality of education for students with disabilities:

1. Greater efforts to integrate special education and general education instructional programs.
2. Movement away from educational services based on type of student disability to curricula that focus on the specific educational needs of the student.
3. Emphasis on increased community and parental involvement in education.
4. School responsibility to ensure equitable individualized learning opportunities for all students.
5. School accountability for student success.
6. Programs that address the academic, physical, social, cultural, and emotional needs of all students.
7. Emphasis on accommodating the needs of all students.
8. School improvement that addresses the needs of all students.

19

Family members, students, educators, friends, and community citizens can play an active role in advocating for beneficial changes in educational programs for students with disabilities and setting a new course for educational excellence.

References

Brolin, D.E. (1989). Life centered career education: A competency based approach (3rd ed.). Reston, VA: The Council for Exceptional Children.

Edgar, E. (1987). Secondary programs in special education: Are many of them justifiable? Exceptional Children, 53, 555-561.

Giangreco, M.F., Cloninger, C.J., Mueller, P.H., Yuan, S., & Ashworth, S. (1991). Perspectives of parents whose children are dual sensory impaired. The Journal of the Association for Persons with Severe Handicaps, 16(1), 14-24.

O'Brien, J. (1987). A guide to life-style planning. In A comprehensive guide to the Activities Catalog. Baltimore: Paul Brookes.

University of Kansas School of Education (1991). Policy considerations on outcomes-based accreditation for students receiving special education services. Lawrence, KS: Author.

Winger, P. (1991). Changing the future of special ed graduates. The Special Edge, 5(7), 1,14.